Conference Summary Report

Setting a Research Agenda for Health and the Humanities

U.S. Department of Health and Human Services
Public Health Service
Agency for Healthcare Research and Quality

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Setting a Research Agenda for Health and the Humanities

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Introduction: A New Era of Interdisciplinary Studies

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In March 2002, the National Endowment for the Humanities (NEH) and the U.S. Agency for Healthcare Research and Quality (AHRQ) convened a conference to explore how historical, philosophical, literary, and other humanities perspectives might improve the quality of health care in America. Some 50 selected experts in the fields of health services research and the humanities convened to develop a research agenda and explore ways to build the capacity to study these issues. The purpose of the conference was to expand interaction between health services researchers and scholars in the humanities to broaden the horizons of medical care.

This conference is truly a fitting tribute to the late Dr. John M. Eisenberg, former director of AHRQ and, without doubt, the inspiration for the conference and for the scope and aspirations of its recommendations. John Eisenberg was truly a Renaissance man–an outstanding clinician, scholar, teacher, medical researcher, and administrator. His interests were broadly encompassing; his reading list ranged from *JAMA* to the sports pages, from Medicare policy deliberations to books on world trade and globalization. John was vitally interested in history and the humanities in the broadest sense, and specifically in the role the humanities can play in the enrichment of medicine. John Eisenberg and William Ferris, the former chairman of NEH, began discussions that led to the conference and its recommendations. John Eisenberg's name and memory were invoked often during the conference, both in prepared speeches and in impromptu comments, as an inspiration to the participants.

The recommendations in this conference summary support our preconference belief that the key to fostering greater involvement of the humanities in health services research lies in cultivating well-planned interdisciplinary research projects. We are pleased to see that these recommendations repeatedly and in various ways support the sponsorship and funding of joint AHRQ-NEH research projects that are interdisciplinary, not just multidisciplinary. Interdisciplinary research strives for cooperative analysis and shared understanding of a phenomenon, starting from the distinct modes of analysis, different kinds of evidence, and separate bodies of explanation employed in two or more disciplines. It seeks to bridge the many obstacles to understanding and communication between the disciplines.

At the opening of the conference, Dr. Edmund Pellegrino of Georgetown University noted that a conference on issues related to reforming and modernizing medical education that was sponsored by NEH about a decade earlier proved to be a "spawning ground" of the modern-day bioethics movement. He suggested that this 2002 conference might prove to be the intellectual birthplace of another groundswell of interest in expanding the reach and influence of the humanities into health services research.

While applauding this buoyant expectation, some conference participants expressed pessimism. Some of them felt that they had been through similar sanguine discussions before and still did not see much progress toward cultivating and funding a growing role for the humanities in medicine.

We, however, endorse Dr. Pellegrino's optimism. We are studying the conference suggestions earnestly. Already, we are funding a number of research projects that meet several of the criteria and goals of the recommendations. In fact, we are pursuing plans to broaden our portfolio of jointly funded research.

So far the two agencies have funded 13 research fellows in two years' funding cycles in grants totaling $479,000. Many research reports on a variety of subjects embracing humanities and medicine are now complete. The following four grant topics provide some idea of the types of interdisciplinary research we have in mind:

- 20th Century Social Attitudes Toward Pain.
- Permissible Harm, Patients' Rights, and Ethical Issues in the Rationing of Scarce Health Care Resources.
- A History of the Right to Health Care in the United States.
- Securing Better Survival for Unfavored Groups in the United States.

All of these grants were awarded to *humanities* researchers. We feel that they mark a new era of understanding and collaboration to expand our agencies' goal of fostering research at the intersection between the humanities and health. With the recommendations outlined in this report, we can more capably plan our next steps.

We at the sponsoring agencies wish to express our gratitude to the participants for their scholarly deliberations that led to these recommendations and to the efforts of the conference workgroup leaders for writing this conference summary.

Setting a Research Agenda for Health and the Humanities

By Emily Abel, Ph.D., M.P.H., University of California, Los Angeles; Charles L. Bosk, Ph.D., University of Pennsylvania; Bruce Jennings, M.A., The Hastings Center; Fitzhugh Mullan, M.D., Health Affairs/Project HOPE; and Neil Swan, B.S.

Background

The National Endowment for the Humanities (NEH) and the Agency for Healthcare Research and Quality (AHRQ) are exploring collaborative research efforts and ways in which humanities scholars can offer their insights to better inform, stimulate, and expand the horizons of the Nation's health care system. AHRQ, in partnership with NEH, conducted a conference, Setting a Research Agenda for Health and the Humanities, to explore how the humanities' historical, philosophical, literary, and other viewpoints might be used to bring new perspectives to the health services research now funded by AHRQ. The conference was held March 14 and 15, 2002, in Potomac, Maryland.

The conference was limited to about 50 invited participants to maximize discussion. The conference and its agenda-setting objectives were the culmination of a November 2000 meeting between AHRQ's then-Director Dr. John M. Eisenberg and NEH's then-Chairman William Ferris. Both men were dedicated to uniting the knowledge and perceptions of scholars in the humanities and their research colleagues in the increasingly technology driven and academically fragmented fields of medicine and health services research. Experts in the fields of health services research and the humanities were selected by the two agencies. They were asked to hold discussions and to recommend a research agenda to foster collaborations between the two fields—that is, to propose innovative interdisciplinary research and funding approaches.

The conference was divided into four subject-area workgroups, each under the direction of an expert discussion leader. To give participants an idea of activities and discussions in the other concurrent workgroup sessions, each workgroup leader reported a summary of that group's dialog at the close of the first day's sessions. At the end of workgroup sessions on the second day, the workgroup leaders reported back with a concise summary of the suggestions and recommendations of each group's participants.

The four workgroup leaders are the coauthors of this article, along with Neil Swan, a medical writer.

Workgroup	Leader
End-of-Life Issues	Bruce Jennings
Family Caregivers	Emily Abel
Patient Safety	Charles L. Bosk
Access to Care	Fitzhugh Mullan

Discussions

Discussions were thorough and wide ranging, yielding some very specific suggestions with somewhat limited support and a number of recommendations, or variations thereof, with broad support. Participants repeatedly lauded the concept of interdisciplinary research and efforts that effectively bridge the traditional gulf between the studies of people and their culture—philosophy, literature, and the fine arts—and the physical or biological sciences and medicine. In fact, one participant pointed to a sense of passion in the depth of support for fostering genuine interdisciplinary approaches in health services research.

It was evident during the discussions that the majority of the participants felt that a collaborative research agenda depends on finding ways to introduce and fund truly interdisciplinary research, as opposed to multidisciplinary research. While multidisciplinary researchers work on a common project, they often work quite independently, guided by the terminology and culture of their own discipline. Over the years, the various academic disciplines have become increasingly specialized, relying on different technologies, terminologies, and accepted procedures. As science and medicine become increasingly specialized, obstacles inadvertently arise that limit the horizons of exploration and discovery across disciplines. These barriers reflect vast differences in disciplinary cultures and entrenched traditions, as well as a failure to communicate across disciplines, a number of participants noted.

Interdisciplinary research can be considered much more a team effort, others pointed out, often with a centralizing leadership, coordination, and robust interaction designed to bridge traditional discipline-based differences. In a truly interdisciplinary effort, team members typically engage in back-and-forth discussions of meanings and terms, language, viewpoints, and approaches that eventually produce a commonly accepted, melded product. Presumably, interdisciplinary research produces findings that are comprehensible and more appealing and meaningful to a broader, more cosmopolitan audience.

Interdisciplinary research in health care requires the perspective of the humanities, participants agreed. This is not because the humanities can add to the breadth of medicine's quantitative knowledge or statistical data, but because the humanities can add to the breadth of medicine's ability to step back and

scrutinize traditional interpretations and fundamental principles underlying today's biomedical research and the practice of medicine, according to a number of speakers. Developing genuine interdisciplinary approaches will require the humanities' core strengths of interpretation, contemplation of values, and use of uninhibited imagination to envision new ways of doing things, participants said.

Those at the conference said the humanities offer great potential to broaden and rejuvenate medicine's horizons by reexamining its foundations, cultural interpretations, and human values, thus opening new pathways to creativity and innovation. Many felt the humanities can offer expansive new "big picture" insights into the widening scope of biomedical research and the practice of medicine at a time when medicine and its practitioners are increasingly specializing in ever-narrower areas of expertise.

The four workgroups recommended quite specific ways to address needs and overcome barriers to welcoming the humanities to each group's subject area. In addition, they recommended a number of overlapping, complementary, or universal approaches to fostering interdisciplinary and collaborative approaches.

Some common points and broad areas of agreement among the four groups follow:

- It is crucial to first step back and make a contemplative, comprehensive, "big picture" examination of our Nation's evolving health care system before proceeding to find specific or detailed methods to foster research collaborations.
- The "two-culture" dichotomy between humanities scholars and health services researchers may never be totally overcome. But some participants warned that a preoccupation with the two-cultures breach could itself become a simplistic excuse for failure—an encumbrance to finding effective ways to address diverging intellectual jurisdictions and introduce interdisciplinary approaches.
- Language and disciplinary jargon and entrenched academic, medical, and institutional traditions produce formidable barriers to interdisciplinary approaches. There is a critical need to understand the basis of these disciplinary barriers and to systematically use rhetorical analysis—the study of the use of language—to improve communications and bridge disciplinary chasms.
- Strategies and government programs designed to increase interdisciplinary approaches—in terms of meaningful involvement of humanities scholars in health care system and medical research—were almost universally hailed as the basis for recommending the collaborative research agenda.
- Boldness and innovation are needed in proposing and testing revisions in research agendas and funding mechanisms to foster collaboration.
- Once new innovative funding mechanisms and strategies to cultivate interdisciplinary research are tested and proven, the concepts and results should be widely disseminated for broad application and replication.

Recommendations

The following recommendations are not a verbatim record or formally ratified set of "marching orders" adopted by conference participants. No votes were taken; there was no detailed documentation of proposed recommendations. Rather, the following should be considered as a broad range of suggestions to AHRQ and NEH.

Broad-Spectrum Recommendations

These broader recommendations are synthesized from the four separate workgroups and a synopsis highlighting areas of agreement that were reached during 10-12 hours of discussions. Two overarching recommendations emerged.

1. Initiate a "Big Picture" Analysis of Health and Health Care.

Foster intellectual exercises to analyze the fundamentals underlying the American health care system in the 21st century. This means reexamining foundations, basic definitions, cultural traditions, and assumptions that influence the practice of medicine and the delivery of health care, as well as the nature and performance of scientific discovery, the influence of corporate interests, and the potential and ethical considerations generated by rapidly unfolding biotechnology advances. The analysis involves the implications of all of these factors and practices on the well-being of society.

Participants envisioned scholarly examinations, within the domains of both the humanities and health services research, of the historical, philosophical, and empirical foundations of health care. This comprehensive "big picture" analysis should be seen as a philosophical exercise and an abstract contemplation of basic beliefs and assumptions about disease, suffering, medicine, and human society. The analysis might involve asking panels of academics philosophical questions such as:

- **What constitutes good health?** Is it more than the absence of disease or infirmity?
- **Who should pay for health care?** The United States is unusual among nations in providing an uneven patchwork system combining public and private insurance and payer programs.

- **Should the United States seriously consider developing equitable ways to ration health resources as demands increase and the population ages?** Some would argue that health services are already rationed, based on the ability to pay.

One participant suggested that this examination of foundations and assumptions underlying medical research, health policy, and the delivery of health care should be based on the concepts of Princeton University anthropologist-ethnographer Clifford Geertz.[1] Considering himself a "social constructionist," Geertz says he believes that all "meaning is socially, historically, and rhetorically constructed."[2] For many years, Geertz has attempted to steer scholarship in his field, anthropology, away from a rigidly scientific model and toward a humanistic, explanatory, interpretive model—a concept that can be used when recommending strategies to infuse humanities perspectives into health services research.

2. Empower a National Summit Conference or Continuing Task Force To Identify and Examine Major Issues.

Analyze selected major issues within a unifying theme such as Nurturing Interdisciplinary Research That Bridges the Worlds of the Humanities and Health Services Research. This conference or continuing task force should examine broad underlying concepts. It should:

- Define interdisciplinary health care research models or prototypes that effectively embrace humanistic viewpoints. What are the models' components and the goals of collaborative research? What are the differences between multidisciplinary and interdisciplinary approaches?
- Examine how best to integrate *experimental* (rigid, empirical, statistical) and *interpretive* (humanistic, explanatory, narrative) approaches to a single research issue.
- Examine the role of rhetorical analysis in seeking strategies to achieve interdisciplinary research goals. How can rhetorical analysis be used to bridge disciplinary chasms by skillfully presenting facts and ideas in clear, convincing, evenhanded, and attractive language?

Some broad cultural issues that might lend themselves to this type of examination by the conference or task force are:

- The meaning of health.
- The concept and components of quality of life.
- The concept of *normalcy*. Is it normal to die? Is it normal to become ill? Or is illness an abnormal status?

More focused and limited areas of examination might include the following:

- Are researchers adequately using the best tools of modern science, including behavioral studies and statistical correlation, to reveal how new health care policies might work in the marketplace to help determine whether policy changes should actually be implemented?
- How can the practical wisdom and experiences of health care professionals best be used to systematically address quality improvement?
- How can policymakers address health care practitioners' natural inclination to put up self-protective defenses to avoid emotional responses to their repeated exposure to death, disability, and disease? To what extent does this response convey the perception of cynicism or indifference?

Specific Recommendations and Suggestions

1. Create Single-Issue Working Groups.

Establish a series of single-issue collaborative working groups to draw up research agendas and goals. These collaboratives would:

- Have a single theme.
- Have a multidisciplinary membership.
- Follow an iterative process.
- Meet repeatedly over an assigned time span.
- Produce multiple products and recommendations.

Goals of the collaboratives would be to:

- Enhance the interdisciplinary culture of health services research and humanities research.
- Develop issues for further research.

Three levels of collaboratives were envisioned:

- **National panels** with members from throughout the United States and various disciplines meeting periodically.
- **University collaborative panels** with members from many disciplines meeting together in a given university setting.
- **Community collaboratives** with individuals from different disciplines and institutions meeting in a specific community.

Illustration: The Family Caregivers workgroup members proposed their group as the core of a national collaborative panel focusing on the sole issue of family caregiving. They proposed adding other members with additional interests and

[1] Geertz C. The interpretation of cultures. New York: Basic Books; 1973.

[2] Olson GA. Clifford Geertz on ethnography and social construction. JAC 1991; 11(2):2-11.

expertise, meeting from one to six times a year, and maintaining regular electronic communications between meetings. The goal would be to develop a specific research agenda for projects on family caregiving, maintaining this concentrated area of emphasis over an extended period. The group expressed enthusiasm and excitement over the potential. If funding agencies (AHRQ, NEH, or other agencies) respond favorably to this suggestion, an allocation of funds would be necessary for travel and administrative support.

2. Assess Innovative Funding Mechanisms.

Create and test new funding mechanisms to foster cross-training of researchers and promote transdisciplinary teaching and collaborative research. Four programs were suggested:

- **Cross-training fellowships.** These fellowships would be designed to provide scholars from the humanities with an opportunity to familiarize themselves with health care settings and also offer health care researchers an opportunity to broaden their horizons in the humanities. These would be training (not research) fellowships, with a primary goal of broadening the experience and the perspective of the individual recipients. Two categories of cross-training fellowships were envisioned, student level and faculty level.
- **Transdisciplinary team teaching grants.** These grants were envisioned as a means to promote transdisciplinary teaching. Academics from the humanities would co-teach selected classes and special course topics with academics from the health sciences, thus providing interdisciplinary curriculum content and novel role models.
- **Transdisciplinary research grants.** These grants would promote collaborative research projects that skillfully fuse the goals, methods, and expertise of the humanities with those of health services research. Several participants felt that basic reforms in the peer-review system would be necessary to streamline the process to avoid cumbersome requirements based on a too-mechanistic approach (e.g., imposition of arbitrary dollar quotas in grants).
- **A special debt-free M.D.-Ph.D. program.** This program would be for physicians who also earn doctorates in the humanities. Workgroup participants noted that for the program to be fruitful, special debt-absolution policies would be required. An M.D.-Ph.D. graduate who bears a heavy tuition debt will be motivated to work as a physician to pay off the debt, thus diminishing the benefit of the additional humanities training.

Collaborative funding is needed. It was suggested that additional sponsors be invited to join in the funding of all of these programs, especially the transdisciplinary grant program. Additional sponsors might include the National Institutes of Health, the Health Resources and Services Administration, the Centers for Disease Control and Prevention, the National Endowment for the Arts, and private foundations.

3. Review and Reform Funding Mechanisms and Peer Review Practices.

- Undertake funding set-aside experiments modeled broadly on the ELSI model. The U.S. Department of Energy and the National Institutes of Health devote 3-5 percent of the annual Human Genome Project budgets to studying the ethical, legal, and social issues (ELSI) related to their genetic research. Conferees generally praised the ELSI set-aside concept as a proven mechanism to move toward interdisciplinary research approaches, particularly in a broad area of current health system concern, such as medical errors. Several members said a set-aside mechanism should contain safeguards to prevent the effort from going off track by concentrating too much on specific questions, at the expense of general questions and issues.
- Within the peer-review mechanism, experiment with changes in membership criteria based on academic discipline, perhaps developing formulas to allocate seats on the panel to ensure a level of input from the humanities.
- Establish trials of special "all-humanities" study sections to solicit and review selected categories of RFPs (Requests for Proposals for grant funding).
- Experiment with other study section membership requirements designed to foster cross-disciplinary understanding and funding decisions.
- Encourage experimental funding approaches and greater use of "research packaging" mechanisms for organizing broad-based research projects, such as Hastings Center and EDC (Education Development Center) "network" models:
  - A Hastings Center model is a packaging concept to seek funding by bringing together an interdisciplinary study group of experts from around the country and from different fields and professions to focus on a specific topic. Over the course of 2-3 years, a task force deliberates on the issue and makes a policy analysis and recommendations that are published in book form. The final product is not only the publication but also the nurturing of the deliberative interdisciplinary process that produced it.
  - The Education Development Center developed the EDC model to produce curricula for training health professionals. It brings together a number of institutions, rather than individual researchers, willing

to become "Centers of Excellence" or "Examples of Best Practices" on a single issue. The institutions form a research network or coalition, and each forms an internal leadership team to work within its own institution to bring about change and improved practices. Information and results are shared regularly among network participants.

- Pursue efforts to identify innovations (such as set-asides) that the Liaison Committee on Medical Education (LCME) can propose as accreditation criteria for medical schools. In addition, accreditation criteria for universities granting doctorates or master's degrees in public health might be enhanced to require the institutions to demonstrate their commitment to interdisciplinary goals, such as by requiring all students to complete a minimum number of credit-hour studies in literature or history.

4. Foster Dissemination of the Findings of Interdisciplinary Research.

- Establish and fund a medical humanities journalism initiative including either:
  - Fellowships for working journalists that allow them to spend time in a university setting working with collaborative projects in medicine or spending time in funded collaboratives.
  - Fellowships for students of medicine or the humanities to spend time working at media organizations such as medical journals, health and science sections of major newspapers, or the electronic media (television and radio).
- Foster public dissemination of collaborative research findings.
  - Assign working journalists as members of interdisciplinary research teams.
  - Require that all RFPs include an information dissemination plan as a component.
  - Promote grants that study and support dissemination activities.

5. Conceptualize bold and innovative mechanisms and areas of research to encourage interdisciplinary studies.

Funding agencies could issue RFP's for specific project areas, such as the following:

- Expand the concept of NEH's summer seminars for college teachers as an effective way to germinate research ideas and enthusiasm for interdisciplinary projects. The original model for NEH seminars in the 1970s should be followed. This model is recognized as a catalyst in pioneering concepts that helped to begin the truly interdisciplinary field of bioethics. Participants agreed that the original format of the seminars, which has been altered over the years, should be considered an important model for replication.
- Foster the development and implementation of demonstration projects to stimulate nontraditional or interpretive ways to address health care issues. One idea is to encourage grassroots community dialog on broad topics such as barriers to access to care. For example, a local readers' theater might demonstrate novel ways to launch community dialog on a specific health topic.
- Hold local interinstitutional regional meetings periodically to generate interest in and encourage proposals for funding community-based collaborative projects.
- Hold a round of joint NEH-AHRQ regional briefings to explain the agencies' evolving efforts to foster interdisciplinary research and to describe funding mechanisms and goals to grant-seeking researchers and scholars.

Suggestions From Individual Workgroups

End-of-Life Issues Workgroup

- Increase interdisciplinary mentoring and develop experimental strategies for one-on-one counseling and teaching. Mentoring offers great capacity-building potential in broadening career perspectives for a modest investment.
- Acknowledge that "disciplinary bias" in reviewing RFPs can work against both health sciences research and the humanities. Study section panels should be composed of reviewers who truly understand and believe in interdisciplinary research. Otherwise, a mechanical allotment of awards (X awards per category) would result in a multidisciplinary process, not a true interdisciplinary process.
- Be open to various alternatives and approaches in reviewing funding mechanisms. Consider the use of outside consultants or creation of ad hoc study sections. Funding agencies might experiment with adjustments in their reviewers' scoring mechanisms to add value for concepts in funding requests that represent values from the humanities
- Examine the viability of developing a sort of "universal RFP template" for a category of grant proposals that responds both to the standard scientific criteria of

hypothesis, data collection, methodology, and analysis and the humanities' need for evaluative criteria and interpretive exercises. (Conferees acknowledged that a universal template might be impossible to achieve, a futile square-peg vs. round-hole pursuit, but they felt the effort still might yield valuable insights.)

- Foster more patient-centered research and also more community-centered research, building on the Missoula, Montana, model supported by the Robert Wood Johnson Foundation. The Missoula project recognizes that death and ways of dealing with death (hospices, funerals, newspaper obituary styles, etc.) are community experiences.

Family Caregivers Workgroup

- The Family Caregivers Workgroup crafted and approved a statement:

  > Although the emphasis at this conference has been on how the humanities can enrich health care, we also want to ask how health care can contribute meaningfully to the quality of research in the humanities. Our answer is that the collaboration could fruitfully call the humanities back to their roots in the practical and the concrete.

- Organize a conference on the issue of expertise, addressing topics such as:
  - How do we define medical expertise?
  - What is the history of skilled medical care delivered at home?
  - To what extent do family members now believe that they are entrusted with decisions that exceed their capabilities?
  - How do family members learn to advocate for patients?
  - How does the shift in the delivery of high-technology care to the home affect the notion of professionalism?
  - To what extent do conflicts about expertise arise between family caregivers and health professionals?

This proposal for a conference on expertise generated great enthusiasm from the workgroup participants, with suggestions for research goals:

- Issue specific RFPs to examine the family as a unit of care within the health care system in relation to chronic illness, end-of-life issues, and disabilities.
- Issue RFPs designed to dramatize family caregiving concepts to the public by developing films, videos, or photo exhibits spotlighting a specific area of interest (e.g., "A Day in the Life of a Family Caregiver") from a humanistic viewpoint.
- Encourage RFPs designed to promote "narrative medicine," using literature and diaries to dramatize the phenomenon of illness from the human, rather than clinical, standpoint. The effort might focus on the "voice of the patient" or use the concept of readers' theater as a method for understanding different perspectives of patients, families, and health care practitioners.

Patient Safety Workgroup

- Recognize that Broad-Spectrum Recommendation No. 1, the "big picture" analysis of health care, has tremendous potential as a unifying theme to build capacity for and inspire interest in interdisciplinary research. Scholars, researchers, and even the news media can be involved, broadening interest and fostering innovation in interdisciplinary approaches. Once launched and drawing news media attention, the broad analysis could become a source of excitement in pursuing new intellectual pathways and a magnet for drawing researchers and scholars from many disciplines.

  Illustration: Patient safety could be studied as part of the "big picture" examination of the historical, philosophical, and empirical foundations of health care. Three broad approaches to examining patient safety are:

  - **Evidence-based medicine (EBM).** In EBM, clinical treatment decisions are based on evidence from research and on the strength of that evidence. The evidence-based medicine movement is broadly accepted and expanding. But medical journals continue to report failures to implement EBM's proven advances in the medical "front lines." Studies show that it can take years for EBM-proven procedures and therapies to be widely adopted. The causes of this failure should be examined and corrective measures should be sought.
  - **Medical errors.** In November 1999, the Institute of Medicine released a report estimating that as many as 98,000 patients die as the result of medical errors in hospitals each year. This assessment should examine the concept of safety (not just patient safety), the history of safety, and organized efforts by industry to advance safety. For example, it should examine various current methods of incident reporting of medical accidents, their effectiveness, and how health care professionals and administrators perceive them. Many error-reducing strategies, such as computer-based drug prescriptions to replace hand-scrawled written prescriptions, have been proven effective yet are adopted only in selected medical

systems. Why? What are the many causes of errors, whether illegible handwriting on drug prescriptions, record-keeping failures, or drug interactions? This study should also examine the basis of resistance by care providers to various safety initiatives.

- **Relationship between patient safety and the public health system.** Patient safety issues should be closely related to the Nation's public health system, which represents an existing and functioning mechanism for addressing patient safety at the national, State, and local levels. Recent concern over bioterrorism has bolstered support for the public health system, a fact that should be leveraged to boost patient safety protections through the public health system. A thoughtful examination of its mission and goals, emphasizing patient safety, would be appropriate.

- Recognize that, at this point, it is very difficult to identify effective case histories of interdisciplinary research because there is little experience in addressing meaningful ways to involve the humanities in health services research.
- Urge funding agencies to recognize that their RFPs are sometimes unintelligible to humanities scholars because of the style and language that is too quantitative, too empirical, too hypothesis-driven. To be sensitive to the research style of a humanities scholar, the RFPs should recognize more qualitative and interpretive measures and fewer quantitative measures. "Sometimes you don't know what your outcomes measures are going to be before you start the research," commented one humanities scholar.
- Be innovative in ways that will cross-fertilize academic interests and pursuits, thus building capacity for future collaborations and originality. "Some physicians hunger for participation in the humanities but they are limited by career restraints," commented one participant. "There needs to be some sort of innovative Federal funding to bridge this gap and provide a way for a clinician to 'hang out' with a different crowd. But this is not research training. You have to provide funding for these 'boundary-walkers' to enrich themselves through something like a sabbatical or a unique grant. We need to think of revolutionary approaches."
- Recognize that medicine, to a large degree, has ignored the voice of the patient … literally. Studies show many patients complaining, "My doctor doesn't listen to me." Research should examine to what extent factors such as managed-care production quotas (the anecdotal limit: 7 minutes per patient) and professional aversion to personal involvement with patients' suffering disrupt the patient-doctor relationship.

Access-to-Care Workgroup

- Recognize that faulty communication, disinformation, distortions, and half-truths promoted by powerful interest groups as well as emotion-laden "language labels" are critical barriers to common understanding and collaboration. When well-financed interest groups launch national advertising campaigns and persuasive television commercials, the results can be devastating to thoughtful public deliberation. Words such as "entitlement," "right," "underserved," "poor," and "socialized medicine" all carry potentially misleading and even false and harmful meanings.
- Focus more attention on the relative merits of new health care interventions to society at large. While coronary artery bypass surgery might extend an 80-year-old patient's lifespan 5 years, thus benefiting the individual, the benefits or detriments to society as a whole must also be weighed.
- Realize that not all health care advances result from breakthroughs. Many quiet advances provide enormous benefits to society that are not fully appreciated. For instance, water sanitation projects in Third World nations can drastically reduce child deaths from diarrhea and thus increase lifespan 50 or 60 years.
- Recognize that the news media and the public are influenced by the "breakthrough mentality" in health care—the idea that a revolutionary technology or "magic bullet" is the pathway to enormous advances in public health. As a result, curative medicine gets much greater attention and public support than preventive medicine, such as disease management, or public health issues, such as water quality and air quality.

Conclusion

Just as there was no official adoption of recommendations, there was no endorsement of a concluding statement at the conference. Repeatedly, however, conference participants said they hoped their brief deliberations would mark the beginning of an era of broader understanding of the importance of building on the contributions of the humanities in medicine and medical research. The fact that two Federal grant-issuing agencies convened the conference is a promising step, they said. Now, many participants added, it is critical that those agencies, and others, seriously review and consider these unofficial recommendations in designing future research strategies that would achieve transdisciplinary and interdisciplinary goals.

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